



MEMBERSHIP MEETING 2016

EURORDIS EXTRAORDINARY GENERAL ASSEMBLY

26 MAY, 2016

EDINBURGH, UNITED KINGDOM



WELCOME TO EURORDIS EXTRAORDINARY GENERAL ASSEMBLY 2016



26 May, 2016
Edinburgh, United Kingdom



EURORDIS
Rare Diseases Europe

WELCOME!

Terkel Andersen, President



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Modification of statutes: Why?

- Current statutes created in 1997 and revised in 2003
- Since then, EURORDIS has seen growth in membership, budget and scope of activities:
 - The Board of Directors deemed it good governance to re-assess the by-laws, and update according to current reality
- Several areas of statutes deemed to be in need of revision including: Name, Objectives, Internal rules (by-laws)



Modification of EURORDIS Statutes

John Dart, General Secretary



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Statutes vs By-laws

Definitions:

- **Statutes** (or articles of incorporation, charters, constitutions, articles of association, etc.) are established when the organization files for incorporation with the appropriate state agency. A Board of Directors gets its authority from the articles. This governing document specifies, for example, its name, the purpose or mission of the organization, place of business, primary officers, dissolution of the organization, etc
- **By-laws** are the set of rules under which the organisation will operate. They typically include such items as (a) number of members, term length, nomination process, committees, and meetings; (b) fiscal year/accounting cycles, committees, and officers' responsibilities; (c) methodologies, tools, and strategies, monitoring and evaluation etc.; and (d) how to amend the by-laws themselves. Typical by-laws of a non-profit organisation will contain the following information: Preamble; Organisation name and acronym; Organisational logo; Basic aim and purpose of organization; Mission statement; Functions; Membership (types, conditions/qualifications of members, status, procedure to become members, rights and obligations, termination); Advisory board (role and functions, qualifications of board members, authority, elections, members); Organisational structure; Asset management (Finance and property, membership fees); Legal status; Contact address;

Statutes vs By-laws

Proposal:

The terms ***statutes*** to now replace what were formally known as by-laws.

The term ***by-laws*** to replace what was formally known as internal rules.

- The ***Statutes*** will be **lighter in content** providing the **overall structure and governance framework** of the organisation

whereas

- The new ***By-laws*** will set out the **rules of the internal processes** for **detailed and enhanced governance** by which EURORDIS operates

Modification of Statutes: Name

- Essentially EURORDIS is known with 3 different names:
 - EURORDIS
 - European Organisation for Rare Diseases
 - Rare Diseases Europe
 - ...And also sometimes as European Rare Diseases Organisation

Proposal: Officially change name to:

"EURORDIS-Rare Diseases Europe

also known as European Organisation for Rare Diseases"

- In this way:
 - We retain the **name recognition** that we have through "EURORDIS"
 - **Streamline the tagline “Rare Diseases + Region/Country”** as committed to by EURORDIS and National Alliances (through the Common Goals & Mutual Commitments) and as included in "Rare Diseases International"

Modification of Statutes: Objectives

The Objectives (Article 1) of the organisation have been updated to reflect current scope of activity.

Following comments received from members after the circulation of the renewed statutes we have introduced the following changes:

- reorganisation of the list of categories of activities that EURORDIS undertakes including the addition of two points (***presented in bold***). This has been done to improve the flow of the list and to give a more accurate account of the scope of EURORDIS' current and future activities.
- addition of a paragraph (***in bold***) providing a brief history of the creation of the organisation in 1997 by the four founding members and acknowledging their contribution to EURORDIS. This was in our original Statutes of 1997 and in the amendment of 2003.

Modification of Statutes: Objectives

"To this purpose, the association undertakes activities in the following categories:

- advocating within European and International institutions for policies that address the needs of Rare Disease patients and their families
- promoting policies and services that bring solutions to people living with rare diseases
- advocating for policies that promote the development and equitable distribution of rare disease medicinal products and treatments
- contributing to rare disease research policy development
- encouraging rare disease patients and organisations to share information, experience and resources and providing them with the platforms to do so
- providing training programmes and resources for the purpose of empowering and strengthening the capacity of rare disease patient representatives
- **facilitating patient advocates and patients active participation in policy implementation, research activities, product life cycle, healthcare and good practices**

Modification of Statutes: Objectives

To this purpose, the association undertakes activities in the following categories (**contn**):

- gathering patient experiences and perspectives to inform policy making
- improving patients' and families quality of life by promoting their fundamental human rights, reducing inequalities, isolation and promoting their social inclusion
- **providing services to patients, their families, patient advocates, patient organisations when they are of unique cross-diseases and cross-national highvalue**
- raising public awareness

Its duration is unlimited."

Modification of Statutes: Objectives

"EURORDIS was created in 1997 by four founding members: the Association Française contre les Myopathies, AIDES Fédération Nationale, Vaincre La Mucoviscidose, La Ligue Nationale Contre le Cancer. They are entitled to full membership of EURORDIS.

Thanks to their support, EURORDIS has been able to become established and maintain its operations as an independent organisation."

Modification of Statutes

Articles 3 & 4 on Membership:

- Changes made reflect the way EURORDIS operates in the last ten years and doesn't create anything new.
- Provides general overview of membership structure (current categories: Full & Associate; Only full members vote)
- Membership criteria now part of By-laws, unchanged – will remain as adopted in 2015

Article 5 on Board of Directors:

- Individuals rather than POs nominated to the EURORDIS BoD
- Individuals are still required to be nominated by a full member of EURORDIS
- BoD & BoO roles & responsibilities now part of the By-laws

Why have individuals on the Board?

- Social and financial responsibilities at stake are much higher today – in need of Board Members who will act as trustees of the organisation
- Experience shows that there are more practical challenges with organisations being represented rather than individuals

Modification of Statutes

Article 10 on Operational Entities:

EURORDIS still relies on the following operational entities:

- Councils (most notably the CNA), Working Groups, Task Forces, Steering committees, Editorial Boards and other entities
 - Further discussion as to participation in these to be had during the General Assembly
- Rules for each Operational Entity now part of By-laws

Article 11 on General Assembly:

- Addition of the possibility to introduce remote voting in the future – should an adequate system be found (required by French law to specifically mention in statutes in order to do so)

Modification of Statutes

Article 19 on By-laws:

Separate By-laws drafting the rules for all internal processes of the organisation to be prepared:

- These already exist for most EURORDIS processes but have not to date been compiled in one document and have been made easily and widely accessible
- The BoD will be responsible for the drafting, adoption, monitoring and updating of the by-laws
- The By-laws will be presented at the next General Assembly 2017 and will be sent and made available to all members. The annual update of bylaws will be made available to all members at each general assembly

By-laws

Process	Governance documents
Membership	<ul style="list-style-type: none"> - Membership Criteria
Board of Directors / Board of Officers	<ul style="list-style-type: none"> - Rules & Responsibilities (BoD, President, General Secretary, Treasurer) - Reimbursement of Directors' expenses
Council of National Alliances	<ul style="list-style-type: none"> - Terms of Reference - Common Goals & Mutual Commitments
Council of European Federations	<ul style="list-style-type: none"> - Terms of Reference - Common Goals & Mutual Commitments (to be established)
EURORDIS representative appointment	<ul style="list-style-type: none"> - Rules & Responsibilities - Call for Expression of Interest - Selection & decision process
EPAC, EPAGs, DITA, TAG, SPAG, Circle of Ambassadors, Rare Disease Day Steering Committee etc	<ul style="list-style-type: none"> - Volunteer Charter - Terms of Reference for each specific group
Project Working Groups	<ul style="list-style-type: none"> - Terms of Reference

By-laws

Process	Governance documents
Rare Diseases International	<ul style="list-style-type: none">- Membership Criteria- Common Goals- Election process- Terms of Reference Council of RDI- Upcoming specific by-laws
Partnerships (POs & Learned Societies)	<ul style="list-style-type: none">- Memorandum of Understanding (MoU)- Letters of Agreement- Policy of Relationship with Commercial Companies & Prevention of Conflict of Interest
Staff	<ul style="list-style-type: none">- Internal Staff Rules
Volunteers	<ul style="list-style-type: none">- Volunteer Charter- ToR for each volunteer group
Access to Documents	<ul style="list-style-type: none">- Access to documents for members + Reports from and Councils to all members

By-laws

Process	Governance documents
Oversight of organisation's operations	<ul style="list-style-type: none">- Strategy- Action Plan- Activity Report- Budget- Financial & Audit Report- Board meeting good practice
Fundraising	<ul style="list-style-type: none">- Principles of good practices for fundraising

Questions & Answers



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Vote on Resolution



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